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ABSTRACT

This monograph presents the recommendations of the 15 organizations belonging to the Consortium for Citizens with Disabilities concerning the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, Public Law 100-146. Each issue is briefly presented with a specific recommendation for changes in the law. Major recommendations are intended to achieve the following: (1) update out-moded definitions and language throughout the Act; (2) add a new priority for Developmental Disability (DD) Councils to increase access and choices for people with disabilities; (3) enhance and strengthen the DD Council role as systems advocate and change agent; (4) make use of the Councils' 1990 Report findings and strengthen the planning process; (5) enhance coordination among Councils, Protection and Advocacy Systems (PA) and University Affiliated Programs (UAP); (6) strengthen the independence of Protection and Advocacy (PA) Systems; (7) strengthen PA client confidentiality and access to records; (8) expand the UAP network into unserved areas; (9) ensure provision of key UAP training initiatives and build training availability in critical areas of unmet need; (10) focus grants of national significance to activities which address the major concerns of the developmental disabilities movement. (DB)

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DEVELOPMENTAL DISABILITIES ACT REAUTHORIZATION

FY 1990
RECOMMENDATIONS OF THE
CONSORTIUM FOR CITIZENS WITH DISABILITIES

Consortium for Citizens with Disabilities

Susan Ames-Zierman - 347-1234
Bill Jones - 588-8252

March 7, 1990

Dear Members of Congress and Colleagues,

The undersigned member organizations of the Consortium for Citizens with Disabilities (CCD) are pleased to enclose CCD's recommendations for the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, P.L. 100-146.

The four programs authorized by the Act have as their goal the independence, productivity and integration into the community of all people with developmental disabilities. CCD's recommendations are designed to further strengthen the DD programs' ability to achieve that goal.

Major recommendations achieve the following:

- update out-moded definitions and language throughtout the Act, including the use of "people first" language
- add a new priority for DD Councils which will increase access and choices for all people with developmental disabilities
- further enhance and strengthen the DD Council role as systems advocate and change agent
- make use of the Councils' 1990 Report fingings and strengthen and planning process
- enhance planning and coordination and strengthen relationships among Councils, Protection and Advocacy Systems and University Affiliated Programs
- strengthen the independence of Protection and Advocacy Systems
- strengthen P&A client confidentially and access to records
- encourage the expansion of the UAP network throughout the country, especially into unserved areas

- o ensure the long-term provision of key UAP training initiatives and begin building training availability in critical areas of unmet need

- o more highly focus grants of national significance to activities which address the major concerns in the developmental disabilities movement.

In most, but not all, instances legislative language has been suggested. New language appears underlined and in bold type. Deletions appear in parentheses.

Some definitions are still being worked on: individual support, family support, community support and prevention. New language will be available in the very near future.

We hope our recommendations will be helpful and that you will call upon us if there is any further information you need. We look forward to working with Congress on these and other issues which may arise to further improve the Developmental Disabilities Act.

Sincerely,

Susan Ames-Zierman
NADDC
Co-chair

William Jones
AAUAP
Co-chair

American Association on Mental Retardation
American Association of University Affiliated Programs
American Occupational Therapy Association
Association for Retarded Citizens/U.S.
Council for Exceptional Children
Epilepsy Foundation of America
Learning Disabilities Association of America
National Association of Developmental Disabilities Councils
National Association of Musical Therapy
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Facilities
National Head Injury Foundation
National Industries for the Severly Handicapped
National Recreation and Park Association
United Cerebral Palsy Associations, Inc.

PART A - GENERAL PROVISIONS

Section 101 - Findings and Purposes

0 ISSUE 1: THE INCIDENCE OF DEVELOPMENTAL DISABILITIES. The number of people who have developmental disabilities has not been updated in statute for almost 20 years. The Administration, upon the advice of several experts in the field, estimates that 1.5% of the population has developmental disabilities. Also, Harris estimates that 46 million Americans have disabilities and that 10% of them have "severe" disabilities.

RECOMMENDATION: Section 101 (a) The Congress finds that ---
(1) In 1990, there are more than (two) three million persons with developmental disabilities in the United States;

0 ISSUE 2: INCLUSION OF 1990 REPORT FINDINGS IN LAW. In the spring of 1990 Developmental Disabilities Planning Councils will submit their 1990 Reports to Congress as authorized by the 1987 amendments. The major findings of the Reports should be included in Congressional Findings. Language will be provided soon, upon completion of the analysis of DD Council Reports.

RECOMMENDATION: The purposes section should be updated to reflect the changes made in 1987.

RECOMMENDATION: Section 101 (b) The purposes of this title are--
(1) to provide assistance to States and public and private nonprofit agencies and organizations to protect and advocate the rights, to train professionals and paraprofessionals and others and to advocate for public policy change and community acceptance to enable (to assure that) all people with developmental disabilities to receive the services, supports and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity and integration into the community;

SECTION 102 - DEFINITIONS

0 ISSUE 3: THE FEDERAL DD DEFINITION. In those few instances where the federal definition of developmental disabilities is currently used for eligibility determination for services, it is difficult to apply it to infants and toddlers.

RECOMMENDED REPORT LANGUAGE: Regarding Section 102(5), although the federal functional definition is excellent for use as an advocacy definition, it is frequently difficult to apply as an eligibility definition for state-financed services. Such use has occurred in only a few states and is being contemplated in others. For infants and toddlers, it is not always possible to determine whether substantial functional limitations exist in three or more of the major life areas, since four of the seven areas are more easily applied to older children and adults (i.e., self-care, self-direction, capacity for

independent living and economic self-sufficiency.) In addition, it may not always be possible to determine for infants and toddlers the extent to which substantial functional limitations exist in the remaining three areas - receptive and expressive language, learning and mobility. Therefore, it is the intent of Congress that infants and toddlers who may not be able to be identified as limited in three of the seven life areas, but who have a clinically determined condition or exhibit a developmental delay may be included under this definition."

O ISSUE 4: LINKING INTEGRATION AND EMPLOYMENT AND CORRECTING PEOPLE FIRST LANGUAGE. The term "integration" does not emphasize integrated employment. A major problem identified in Council 1990 Reports is that most people with developmental disabilities who are working are not, in fact, working in integrated, "regular" jobs. Also, many consumers object to the term "home-like settings," feeling that a home should be a home.

RECOMMENDATION: Section 102(8)(B) The term "integration" means---

(A) the---

(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens

(ii) participation by persons with developmental disabilities in the same community activities, including employment, in which (non-disabled) citizens without disabilities participate, together with regular contact with (non-disabled) people without disabilities, and

(B) the residence by persons with developmental disabilities in homes (or in home-like setting) which are in proximity to community resources, together with regular contact with (nondisabled) citizens without disabilities in their communities.

O ISSUE 5: CLARIFICATION OF PRIORITY ACTIVITIES. Clarification is needed regarding the audiences of policy-makers whom Councils address.

RECOMMENDATION: Section 102 (9)B(B(iv) The term "priority area activities" includes, with respect to Federal priority areas or a state priority area---

(A) activities to increase the capacities and resources of public and private nonprofit entities and others to develop a system for providing specialized services or special adaptations of generic services or other assistance which responds to the needs and capabilities of persons with developmental disabilities and their families and to enhance coordination among entities:

(B) the---

(i) conduct of studies and analyses

(ii) gathering of information;

(iii) development of model policies and procedures; and

(iv) presentation of information, (models), approaches, strategies, findings, conclusions and recommendations to local, state and federal executive and legislative branch policymakers

in order to enhance opportunities for persons with developmental disabilities, including the enhancement of a system for providing or making available specialized services or special adaptations of generic services for persons with developmental disabilities and the families of such persons.

O ISSUE 6: PROHIBITION ON FUNDING ON-GOING SERVICES. There are still a few Councils which are funding on-going direct services for lack of State will or ability to obtain alternative funding for the state agency operating the service. While Congress has attempted to make clear that this is not appropriate, these Councils are unable to change direction for a variety of reasons. The statute currently states:

Section 102 (9)(C) the demonstration of new ways to enhance the independence, productivity and integration into the community of persons with developmental disabilities, such as model demonstrations which, if successful, will be made generally applicable through sources of funding other than the funding under this title, including new ways to enhance specialized services or special adaptations of generic services for persons with developmental disabilities and the families of such persons.

RECOMMENDED REPORT LANGUAGE: "Regarding model demonstrations authorized under Section 102(9)(C), Congress intends that Part B funds may be used for direct services only when doing so is part of a short-term strategy in advocating for systems change or on-going funding for such services. Part B funds are not intended to be used as a long-term funding source for services."

"It should further be noted that the extensive statutory definitions of services and supports are provided as guides to the states and are intended to serve as goals toward which service providers should strive and which the Planning Councils should use to evaluate how well services address the independence, productivity and integration into the community of people with developmental disabilities."

O ISSUE 7: NEW PRIORITY AREA. Access and choice issues have become increasingly important and have been repeatedly identified in Council 1990 Reports as a major barrier requiring priority attention. Case management is only one element of access. A new priority area is proposed which includes, but goes beyond case management, to address barriers to access and choice. The barriers to opportunities and services which currently exist, including eligibility barriers, need to have special focus and require a variety of strategies to overcome them. Serious gaps exist in most states to case management and information and referral on the local level. Parents and people with disabilities have repeatedly complained of lack of coordinated services, lack of knowledge of the existence of services, having to travel long distances to receive the information they need, etc. These stories have validated long-held views that states must increase their focus on the design of such systems, rather than permitting disparate fundings streams to create uncoordinated systems that are not "user friendly." The issue of quality is

increasingly on states' agendas as is the need to help the general public to understand the needs and capabilities of people with developmental disabilities as they enter local communities as neighbors and to help build local networks of support. As people with disabilities and parents struggle through the service system, they need assistance to organize themselves for concerted action to assist themselves and their family members, through various empowerment and coalition initiatives.

RECOMMENDATION: Section 102 (10) The term "Federal priority areas" means community living activities, employment activities, child development activities and (case management activities) activities to increase access and choice.

Section 102 (16)(A) The term "activities to increase access and choice" means activities that increase access, choice and opportunities for the exercise of rights, citizenship and community participation by people with developmental disabilities and/or their families, including activities which:

(i) eliminate barriers to access and eligibility for services, supports and other assistance;
(ii) improve systems design including the encouragement of the creation of locally-based state-wide case management and information and referral systems;
(iii) improve the quality of services, supports and other assistance through activities such as citizen monitoring, community and neighborhood involvement, public education and awareness to increase community acceptance, and coalition development and support.

(B) The term "case management: means ..(retain as currently defined).

0 ISSUE 8: DEFINE INDIVIDUAL, FAMILY AND COMMUNITY SUPPORT. As referenced in the definition of "community living activities," family support services are defined in statute; however, additional clarification is required. Neither individual nor community supports are defined.

RECOMMENDATION: Section 102 (12) the term "community living activities" means such priority area activities as will assist persons with developing disabilities in developing or maintaining suitable residential arrangements and supports in the community, including (nonfinancial supports) individual, family and community supports (services).

Section 102 (12)(A) The term "family support (services)" means services, supports and other assistance, primarily to parents with children with developmental disabilities, designed to

(A) strengthen the family's role as primary caregiver;
(B) prevent inappropriate out-of-the-home placement and maintain family unity and
(C) reunite families with members who have been placed out of the home.

Such term includes, but is not limited to respite care, personal care, parent training and counseling, support for elderly parents, vehicular and home modifications, assistance with extraordinary expenses associated with the needs of the child with a disability, and other individualized services, supports and assistance.

Section 102 (12)(B) The term "individual supports" means services, supports and other assistance designed to enable individuals with developmental disabilities to be independence, productive and integrated into their communities, designed to

(A) enable the individual to master his or her environment, permitting the most independent life possible

(B) prevent inappropriate placement into a more supervised living arrangement and

(C) enable the individual to take advantage of activities in the community, including, work and recreation.

Such term includes, but is not limited to personal attendant services, vehicular and home modifications, support at work, transportation, and other services, supports and assistance.

Section 102 (12)(C) The term "community supports" means activities which enable communities to provide services, supports and other assistance to people with developmental disabilities and their families designed to

(A) assist neighborhoods and communities to understand the needs of people with developmental disabilities and their families

(B) develop local networks which can provide informal support

(C) enable communities to be accessible to and offer its resources and opportunities to people with developmental disabilities and their families.

RECOMMENDED REPORT LANGUAGE: People with developmental disabilities require supports at various levels. Assistance provided directly to the individual (individual supports) can enable children to take advantage of educational opportunities and to develop friendships and interests and can enable adults to be productive at home and on the job and to take advantage of leisure time. Families also require assistance in supporting their family member with a disability. Family support is intended primarily to ensure that the family has the ability to raise their child at home by relieving the strains inherent in their family situation. When the family member is an adult, supports are provided directly to the individual with a disability. Finally, communities are where people with developmental disabilities want to live. Increasingly, living arrangements in situations where people with disabilities interact with people without disabilities create opportunities for true integration, the development of informal networks of friends, colleagues and associations. Communities need support (community support) to organize around people with disabilities, to assist in the true integration into community life which is the goal of the DD Act.

O ISSUE 9: DEFINE P&As. UAPs and Councils are defined in statute, P&As are not.

RECOMMENDATION: Section 102 (21) The term "Protection and Advocacy System" means a Protection and Advocacy System established under Section 142.

O ISSUE 10: DEFINE ASSISTIVE TECHNOLOGY. Congress passed the Technology Act subsequent to the 1987 amendments to the DD Act. The DD Act definition of "assistive technology" should be consistent with the Tech Act.

RECOMMENDATION: Section 102 (22) The term "assistive technology" means the systematic development and application of technology, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by, persons with developmental disabilities in areas including education, employment, supported employment, transportation and independent living and other community living arrangements and includes assistive technology devices and assistive technology services.

(22)(A) "Assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities.

(22)(B) "Assistive technology service" means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes

(i) the evaluation of the needs of an individual with developmental disabilities, including a functional evaluation of the individual in the individual's customary environment;
(ii) purchasing, leasing or otherwise providing for the acquisition of assistive technology devices by individuals with developmental disabilities;
(iii) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing of assistive technology devices;
(iv) coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs;
(v) training or technical assistance for an individual with developmental disabilities, or, where appropriate, the family of an individual with developmental disabilities; and
(vi) training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of individuals with developmental disabilities.

O ISSUE 11: DEFINE DESIGNATED STATE AGENCY. DD Councils' relationships with their designated state agency have improved since 1987; however, there is still stress in some states. Role definition is needed to clarify and improve relationships in those states.

RECOMMENDATION: Section 102 (#) The term "designated state agency" means the agency which, on behalf of the state, shall receive, account for and disburse, at the direction of the State Planning Council, Part B funds and provide required assurances and other administrative support services.

0 ISSUE 12: DEFINE PREVENTION. Prevention has been mentioned in the DD Act for many years, but has never been defined.

RECOMMENDATION: Section 102 (24) The term "prevention" means activities which address the causes of developmental disabilities and the exacerbation of functional limitations, such as activities to

(i) eliminate or reduce the biological, environmental and social factors which cause or pre-dispose individuals to developmental disabilities or which increase the prevalence of developmental disabilities;
(ii) increase the early identification of existing problems to eliminate circumstances that create or increase functional limitations;
(iii) minimize the long-term effects of developmental disabilities and/or mitigate against the effects of developmental disabilities.

RECOMMENDED REPORT LANGUAGE: "Prevention encompasses a broad range of activities which could be considered under child-development, community living, employment, access and choice or under a state priority. Such activities should be consistent with state plan objectives in any of the priority areas for which they are deemed by the Council to be appropriate."

0 ISSUE 13: COORDINATION AMONG THE THREE DD PROGRAMS. In most states, Councils, P&As and UAPs coordinate their activities and cooperate well. In a few, however, the three programs do not sufficiently coordinate.

RECOMMENDED REPORT LANGUAGE: "The functions of Councils, P&As and UAPs are different but are inter-related and inter-dependent. Congress encourages frequent, regular communication and coordination between and among the programs to ensure that state-wide planning considers holistically the policy, programmatic, legal, training and research needs of people with developmental disabilities and those who plan, administer and provide services, supports and other assistance to them. In addition to P&A and UAP membership on DD Councils, increased interaction is encouraged. To the extent possible, representatives of each of the three programs should be included as advisors to the activities of the others and should be represented as members of advisory boards or similar bodies where appropriate."

SECTION 103 - FEDERAL SHARE

0 ISSUE 14: POVERTY AREA MATCHING RATE. The Administration has, at times, disallowed poverty area matching rates for grantees in some states because the grantee's mailing address or main office was not physically located in the poverty area, despite the fact that activities undertaken were solely focused on poverty areas. An example is a training project for Hispanic professionals

and para-professionals in developmental disabilities. The Council's goal was to ensure improvement in the outreach and quality of services in Hispanic poverty areas. Because the curriculum was being developed and the training given in a non-poverty area, the 90% matching rate was disallowed. Another example was a Council's development of brochures on developmental disabilities in Spanish for distribution through physicians, local hospitals, churches and Hispanic community organizations.

RECOMMENDATION: Section 103 (a) The Federal share of all activities supported by an allotment to the State under Part B may not exceed 75% of the aggregate necessary costs of all such (projects) activities, as determined by the Secretary, except that in the case of (projects located in) for those activities specifically designed to benefit urban or rural poverty areas, the Federal share of all such (projects) activities may not exceed 90% of the aggregate necessary costs of such (projects) activities, as determined by the Secretary."

Section 103(b) The Federal share of (any project to be provided through grants) funds supporting activities under Part B may not exceed 75 percent of the necessary cost of such (project) activities, as determined by the Secretary, except (that if the project is located) in those activities specifically designed to benefit an urban or rural poverty area, the Federal share may not exceed 90 percent of the project's necessary costs as so determined.

O ISSUE 15: CLARIFY DISTINCTION BETWEEN PROJECTS AND ACTIVITIES. Not all activities conducted and "matched" under the Basic State Grant are "projects." Clarification is needed.

RECOMMENDATION: Section 103(c) The non-Federal share of (the cost of any project assisted by a grant or allotment under this title) the Part B program may be provided in kind.

SECTION 107 - REPORTS

O ISSUE 16: UPDATE COUNCIL ANNUAL REPORT REQUIREMENTS. The Council Annual Reports section should be updated to reflect the results of the 1990 Reports.

RECOMMENDATION: (a) By January 1 of each year, the State Planning Council of each State shall prepare and transmit to the Secretary a report concerning activities carried out during the preceding fiscal year with funds paid to the State under Part B for such fiscal year. Each such report shall be in a form prescribed by the Secretary by regulation and shall contain--

(1) a description of such activities and the accomplishments resulting from such activities

(2) a comparison of such accomplishments with the goals, objectives and proposed activities specified by the State in the State plan submitted under section 122 for such fiscal year

(3) an accounting of the manner in which funds paid to a state under Part B were expended;

(4) a description of the State Planning Council's response to significant actions taken by the State with respect to each annual survey report and plan of corrections for cited deficiencies prepared pursuant to section 1902(a)(31)(B) of the Social Security Act with respect to any intermediate care facility for the mentally retarded in such State; and

(5) a description of the progress made in the State in, and any identifiable trends concerning, the setting of priorities for, policy reform concerning, (and) advocacy for and other actions on behalf of persons with developmental disabilities which are attributable to physical impairment, mental impairment or a combination of physical or mental impairments, particularly unserved and underserved groups, including any other subpopulation of persons with developmental disabilities (including minorities) and a summary of actions taken to improve access to services for unserved and underserved groups that the State Planning Council may have identified in their 1990 Reports and/or their on-going work.

0 ISSUE 17: UPDATE SECRETARY'S ANNUAL REPORT REQUIREMENTS. The section regarding the Annual Reports submitted by the Secretary to the Congress also needs to be updated to reflect actions taken to address the 1990 Reports.

(c)(1) By April 1 of each year, the Secretary shall prepare and transmit to the President, the Congress and the National Council on (the Handicapped) Disability Policy a report which describes--

(A) current language

(B) current language

(C) The progress made by States in, and any identifiable trends concerning, the setting of priorities for, policy reform concerning, (and) advocacy for, and other actions on behalf of persons with developmental disabilities attributable to physical impairment, mental impairment, or a combination of physical and mental impairments, particularly unserved and underserved groups, and any other subpopulation of persons with developmental disabilities (including minorities) that State Planning Councils may (identify) have identified under section (b)(3) and 122(f) and a summary of actions taken to improve access to services for such groups.

SECTION 108 - RESPONSIBILITIES OF THE SECRETARY

0 ISSUE 18: IMPROVE COMMUNICATION BY THE INTERAGENCY COMMITTEE. The DD field knows little about the activities of the federal interagency committee's activities and the implications of its decisions and actions.

RECOMMENDATION: Section 108(b) Within ninety days after the date of enactment of the Developmental Disabilities Act of 1984, the Secretary of Health and Human Services and the Secretary of Education shall establish an interagency committee composed of representatives of the Administration for Developmental Disabilities of the Department of Health and Human Services, the Office of Special Education and Rehabilitative Services of the Department of Education, the Department of Labor, and such other Federal departments and agencies as the Secretary of Health and Human Services and the Secretary of Education consider appropriate. Such interagency committee shall meet

regularly to coordinate and plan activities conducted by Federal departments and agencies for persons with developmental disabilities and such meetings shall be open to the public . A timely announcement of the place, date and time and the minutes of all such meetings are to be sent to Developmental Disabilities Planning Councils, Protection and Advocacy Systems, University Affiliated Programs and interested national disability organizations.

SECTION 110 - RIGHTS OF (THE DEVELOPMENTALLY DISABLED) PEOPLE WITH DEVELOPMENTAL DISABILITIES

0 ISSUE 19: EMPHASIZE THE IMPORTANCE OF THE BILL OF RIGHTS. The Rights Section needs more prominence in statute. Move from Section 110 to new Section 102.

0 ISSUE 20: UP-DATE NON-AVERSIVE LANGUAGE. The non-aversives language has become out-moded and does not reflect current thinking in the disability community.

RECOMMENDATION: 110(3) The Federal Government and the States both have an obligation to assure that by one year from the date of enactment of the Developmental Disabilities Act amendments of 1990 public funds are not provided to any institutional or other residential program for persons with developmental disabilities that-

(B) does not have the following minimum standards:

(i) current law

(ii) current law

(iii) (Prohibition of the use of physical restraint on such persons unless absolutely necessary and prohibition of the use of restraint as a punishment or as a substitute for a habilitation program.) Policies and procedures for the use of positive, non-aversive behavior therapy programs.

(iv) (Prohibition on the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantitites that interfere with services, treatment or habilitation for such persons.) The assurance that individuals with developmental disabilities have the same right to be free from harm, hazardous procedures and physical and/or chemical restraint as do individuals without disabilities; that under no circumstances will procedures be used on individuals with developmental disabilities which could create pain or tissue damage and which would otherwise be considered cruel and unusual punishment and that procedures shall not cause the dehumanization of individuals through means such as social degradation, social isolation, verbal abuse, ridicule or humiliation.

RECOMMENDED REPORT LANGUAGE: This does not exclude from eligibility for public funds those programs which administer neuroleptic medications, or other psychotropic medications, for treatment and therapeutic purposes under the supervision of qualified clinical personnel.

0 ISSUE 21: UP-DATE REGULATORY CITATION. An out-dated reference to the ICF/MR regulations should be made current.

RECOMMENDATION: Section 110(4) All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable outcome for those served and--

(A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative or rehabilitative services, which are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on (January 1, 1974 [30 Fed. Reg. pt.II]) October 3, 1988 as appropriate when taking into account the size of institutions and the service delivery arrangements of the facilities of the programs;

PART B - FEDERAL ASSISTANCE FOR PLANNING PRIORITY ACTIVITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

SECTION 122 - STATE PLAN

0 ISSUE 1: AMPLIFY THE REVIEW OF OTHER STATE PLANS. The State Plan review section does not adequately address all the programs which affect people with developmental disabilities, particularly those that do not have "state plans" per se.

RECOMMENDATION: Section 122(b)(2) The plan must--

(C) describe and provide for the review annually and revision of the description not less often than once every three years (i) the extent and scope of services, supports and other assistance being provided, or to be provided, to persons with developmental disabilities under such other (State plans for) federally-assisted programs that the state conducts and in which persons with developmental disabilities are or may be eligible to participate, including programs relating to education, job training, vocational rehabilitation, public assistance, medical assistance, social services, child welfare, maternal and child health, aging, programs for children with special health care needs, housing, transportation, technology, comprehensive health and mental health and other such (plans) programs as the Secretary may specify, and

RECOMMENDED REPORT LANGUAGE: "Not all federally-assisted programs require State plans, per se; however, it is the intent of Congress that State Planning Councils use such State plans when available, along with other relevant policy documents and reports, as tools for analyzing the situation in each State and to assist the Council in its advocacy efforts with particular federally-assisted programs. Councils should specify in their State Plans which federally-assisted programs without state plans they will review, based upon state plan objectives, and describe how such review is seen as a component of a larger strategy of investigation into the operation of the service delivery systems on behalf of all people with developmental disabilities."

0 ISSUE 2: UP-DATE STATE PLAN REQUIREMENTS. As a follow-up to the 1990 Reports, continued analysis of the Reports' information should be a requirement of the State Plan development process. The State Plan process would not repeat the activities of present Section 122(f)(1) and (2) but rather use the information gathered as a basis for ongoing planning. Also, the State Plan should include information addressing the implementation of the State 1990 Report recommendations since these recommendations will direct Basic State Grant activities for years to come and will be part of Councils' on-going planning process.

RECOMMENDATION: Section 122 (b)(5)(B) The plan must provide for the review and revision not less often than once every three years, of the comprehensive Statewide plan to ensure the existence of appropriate planning, financial support and coordination, and to otherwise appropriately address, on a

Statewide and comprehensive basis, urgent needs in the State for the provision of services for persons with developmental disabilities and the families of such persons. Such review and revision, and examination under subparagraph (A) shall take into account the reviews and analyses conducted, and the report prepared, under subsection (f), and shall at a minimum, include--

(i) an analysis of such priority areas in relation to limited support or lack of support for persons with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) an analysis of criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may be causing persons with developmental disabilities to be excluded from receiving such services:

(iii) an analysis of the special and common needs of all subpopulations of people with developmental disabilities.

([iii]) (iv) an analysis of services, assistive technology or knowledge which may be unavailable to assist persons with developmental disabilities;

([iv]) (v) an analysis of existing and projected fiscal resources;

(v) (vi) an analysis of any other issues identified by the State Planning Council; and

([vi]) (vii) the formulation of objectives in both policy reform and service demonstration to address the issues described in clauses (i) through ([v]) (vi) for (all) subpopulations, including unserved and underserved, identified by the State Planning Council and other issues as identified in the reports required in Section 122(f)(4).

RECOMMENDATION: Section 122 (b)(5)(D)(i) The plan must provide that not less than 65 percent of the amount available to the State under Section 125 will be expended for activities in the Federal priority area of employment activities and, at the discretion of the state, activities in any or all of the three other Federal priority areas and a State priority area, the conduct and analyses specified in clauses (i) through (v) of subparagraph (B) (and the implementation of paragraph (d) and subsection [f]) and activities which address the implementation of recommendations made in the report required under Section 122 (f)(4), including those which address unserved and underserved populations.

RECOMMENDATION: Section 122 (f)(1) - add after the last sentence the following: "Each Council shall use the results as contained in the report required under Section 122(f)(4) as part of the activities specified in Section 122(b)(5)(A) and (B)." Delete Section 122 (f)(3). Section 122 (f)[4](3)(B) - add after the last sentence - "Results and other findings contained in the report required under Section 122 (f)(4) shall be used as part of the review required in Section 122(b)(5)(A) and (B). Delete Section 122(f)(5).

O ISSUE 3: UP-DATE COUNCIL ROLE VIS-A-VIS STATE PLAN. The term "administration of the state plan" is no longer appropriate. The designated state agency no longer supervises the implementation of the state plan; the Council does.

RECOMMENDATION: Section 122 (b) In order to be approved by the Secretary under this section, a State Plan must meet the following requirements:

(1)(A) The plan must provide for the establishment of a State Planning Council in accordance with section 124.

(B) The plan must designate the State agency (hereafter in this part referred to as the "designated State agency") which, on behalf of the state, shall (administer or supervise the administration of the State Plan) receive, account for and disburse, at the direction of the Planning Council, Part B funds, provide required assurances and other administrative support services.

O ISSUE 4: STATE MATCH. In states where the designated state agency provides more than half of the required administrative costs, these funds are not considered as part of the aggregate match for the program, penalizing states which make an extra commitment to support the Basic State Grant Program.

RECOMMENDATION: Section 122 (d)(1) At the request of any State, a portion of any allotment or allotments of such State under this part for any fiscal year shall be available to pay one-half (or such smaller share as the State may request) of the expenditures found necessary by the Secretary for the proper and efficient (administration of the State plan approved under this section) exercise of the functions of the state designated agency except that not more than 5 per cent of the total of the allotments of such State for any fiscal year, or $50,000, whichever is less, shall be available for the total expenditures for such purpose by (all of) the State agenc(ies)y designated under subsection (b)(1)(B). (for the administration of supervision of the administration of the State plan.) Payments under this paragraph may be made in advance or by way of reimbursement, and in such installments, as the Secretary may determine. Expenditures in excess of the one-half of the 5% or $50,000 may be included in the computation of the aggregate match.

O ISSUE 5: COUNCIL PLACEMENT IN GOVERNMENT. Councils need the option to initiate a request that the Governor review the designated state agency, particularly those which chose to remain in a service providing agency. There are some Councils which wanted to change agencies and were supported by public comment but which had insufficient time or power to make the change. Additional provisions are needed.

RECOMMENDATION: Section 122(e) (5) After October 1, 1990, the Planning Council, at its discretion, may initiate a request for a review of the designated State agency by the Governor .

SECTION 124 - STATE PLANNING COUNCILS

O ISSUE 6: UP-DATE THE ROLE OF THE COUNCIL. The role, responsibilities and practices of State Councils need further amplification in statute.

RECOMMENDATION: Section 124 (a) Each State which receives assistance under this part shall establish a State Planning Council (which will) to serve as an advocate for all persons with developmental disabilities and to plan, coordinate and advocate for changes in public policy, including financing, administration and delivery of services and supports for the furtherance of independence, productivity and integration into the community of all people with developmental disabilities and their families.

O ISSUE 7: COUNCIL MEMBER APPOINTMENTS. Governors either wittingly or unwittingly can thwart the effectiveness of DD Councils by failing to promptly make Council appointments. Currently, the statute states:

Section 124 (b)(1) Members of the State Planning Council shall be appointed by the Governor of the State from among the residents of that State.
(2) The Governor of each state shall make appropriate provisions for the rotation of membership on the State Developmental Disabilities Planning Council.

RECOMMENDED REPORT LANGUAGE: "Far too frequently when vacancies occur on Councils, Governors do not appoint new members in a timely way. This can affect the required membership balance on the Council and thwart the effectiveness of Councils. Congress urges Governors to make such appointments within a reasonable time-frame and with input from the Council and other interested disability organizations."

O ISSUE 8: COUNCIL AUTHORITY OVER BSG BUDGET AND STAFF. In order to ensure that the State plan is appropriately implemented, Councils must have clearer authority over Basic State Grant funds. Also, Councils' effectiveness can be harmed when the designated state agency denies staff to Councils or diverts staff time to activities other than those directed by the Council. Also, unless the Council and designated agency have an agreement which clearly defines the supervision and evaluation of Council staff, the Executive Director serves "two masters" - his/her immediate supervisor in the designated state agency and the Council chairperson. While these situations have improved considerably since the 1987 amendments, there are still significant problems in many states.

RECOMMENDATION: Section 124 (c)(1) Each State Planning Council (may) shall prepare and approve a budget using amounts paid to the State under this part to fund all activities funded under Part B (except the 5% or $50,000 for administrative support) and to hire such staff and obtain the services of such professional, technical and clerical personnel consistent with State law as the State Planning Council determines to be necessary to carry out its functions under this part. Through a process consistent with state law or regulations, the Council Director shall be hired by the Council, shall be supervised and evaluated by the Council Chairperson or a group of Council members duly authorized by the Council, and shall hire and supervise all other staff to the Council.

RECOMMENDED REPORT LANGUAGE: "Most Council staff members are state public employees and, while personnel costs are covered by Federal funds, States have sometimes prevented the Council from hiring new Council staff or filling staff vacancies if State government hiring freezes are taking place. Because at least half of the members of the Planning Council are unpaid volunteers, this lack of adequate staff imposes great burdens on Council members. Congress intends that States facilitate to the greatest extent possible the timely and adequate staffing of State Planning Councils."

0 ISSUE 9: RESPONSIBILITY FOR STATE PLAN DEVELOPMENT. For many years, Councils have been responsible for overseeing state plan development and implementation. The statute needs to be brought into line with practice, by deleting reference to the joint development of the State Plan.

RECOMMENDATION: Section 124(d) Each State Planning Council shall --

(1) Develop (jointly with the state agency designated under section 122(b)(1)[B]) the State plan required by this part including the specifications of Federal and State priority area activities under section 122 (b)(5)(D)(i).

SECTION 125 - STATE ALLOTMENTS

0 ISSUE 10: INCREASE MINIMUM ALLOTMENTS. The minimum allotments are much too low to sustain the basic operations, functions and purposes of the Basic State Grant Program.

RECOMMENDATION: Section 125(a)(3)(A) Except as provided in paragraph (4), for any fiscal year the allotment under paragraph (1)--

(i) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Mariana Islands, or the Trust Territory of the Pacific Islands may not be less than ($160,000) $200,000, and

(ii) to any other state may not be less than the greater of ($300,000) $350,000 or the amount of the allotment (determined without regard to subsection (d) received by the state for the fiscal year ending September 30, (1984) 1987.

(4) In any case in which amounts appropriated under section 130 for a fiscal year exceed ($60,000,000) $75,000,000, the allotment under paragraph (1) for such fiscal year--

(A) to each of American Samoa, Guam, the Virgin Islands (etc.) may not be less than ($200,000) $250,000 and

(B) to each of the several States, Puerto Rico or the District of Columbia may not be less than ($350,000) $500,000.

SECTION 130 - AUTHORIZATION OF APPROPRIATIONS

0 ISSUE 11: PROGRAM FUNDING. In the past 10 years, the DD programs have lost more than 30% of their purchasing power, causing great strains in the program as additional responsibilities have been mandated.

RECOMMENDATION: Section 130. For allotments under Section 125, there are authorized to be appropriated $81,270,000 for fiscal year 1991, $85,335,000 for fiscal year 1992, and $89,600,175 for fiscal year 1993.

PART C - PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

O ISSUE 1: INDEPENDENCE OF PROTECTION AND ADVOCACY BOARDS FROM PROVIDERS OF SERVICES. The majority of P&A agencies are governed by Boards of Directors in non-profit organizations. It is essential that the governing boards of P&A agencies are free from interference in the appropriate running of the agency. Several states allow the Governor to appoint some or all of the Board members. This has resulted in undue involvement in certain situations which could negatively affect the rights of P&A clients and raise questions about the provision of conflict-free advocacy.

RECOMMENDATIONS:

(1) Define independence of P&As to prohibit gubernatorial or other service providers ability to appoint Board members in non-profit agencies serving as the designated agency. Amend the assurance section to provide this requirement.

(2) Allow three years for states which have gubernatorial appointments to phase out the practice. In the alternative, allow for only a percentage (1/3) of appointments for those agencies that have gubernatorial appointments.

(3) Prohibit service providers from serving as board members in all protection and advocacy agencies.

RECOMMENDED REPORT LANGUAGE: The Committee believes that to assure conflict-free advocacy services, the governing boards of Protection and Advocacy Systems should not consist of providers of services to persons with developmental disabilities who may potentially be the focus of the advocacy of the P&A on behalf of the person. However, the Committee does not intend to eliminate providers of legal or advocacy services which do not provide other essential direct services to people with developmental disabilities.

O ISSUE 2: REDESIGNATION OF P&As. Redesignation for good cause has been part of the Act for some time. However, the Administration on Developmental Disabilities has not fully defined the term or provided a process for such redesignation. Instances have occurred where the Governor has not notified the agency in advance of the intent to redesignate and has failed to give adequate reasons for the redesignation.

RECOMMENDATION: Provide a specific process for redesignation which:

(1) Requires that the Governor notify the agency of the intent to redesignate and the reasons that justify good cause through prior written notice.

(2) Provides for the agency to respond to the concerns expressed in the redesignation notice.

(3) Requires an opportunity for the disability community and the general public to present its input, including a process which allows written and oral comments to be made in a reasonable time period.

(4) Provides, where appropriate, a corrective action mechanism for the agency to respond before actual redesignation occurs.

(5) Provides a specific definition for good cause in the statute.

(6) Provides that ADD develop a protocol for assessing whether the Governor has met the good cause requirement including appointment of an independent hearing examiner.

0 ISSUE 3: CLIENT CONFIDENTIALITY. There is no specific language in the Act which provides protection of privacy of clients who are being represented by P&A agencies. As the federal agency conducts compliance reviews, there is the potential for disagreement over the need to see identifying information. The Department should have full power to review the work of the agency in order to assure the proper expenditure of federal funds and that quality advocacy services are being provided. However, as P&A agencies are legally based organizations, client privacy and confidentiality of records must be assured.

RECOMMENDATION: Clarify that the federal oversight agency (Administration on Developmental Disabilities) may not have access to information in the case files of clients that would identify them unless clients waive their right to confidentiality. Provisions for access to certain information for federal oversight in the case of fraud or malpractice and compliance with statutory mandates could be included.

0 ISSUE 4: ACCESS TO RECORDS. Problems continue to surface throughout the country on refusal to allow access to clients, facilities and records. Several court cases have been instituted successfully to allow access, (e.g. Mississippi P&A v. Cotton). While the courts have so far consistently upheld P&A right to access, the cases are a costly use of P&A limited resources and do not deal with the substantive issues of rights violations. Furthermore, the P&A experience has been that many facilities, particularly large institutions, are very closed environments with little meaningful outside exposure, and until P&As can gain access to them, P&As cannot start addressing the rights violations and abuse and neglect incidents. Many of the largest institutions are in rural communities which only reinforces the closed environment of those facilities.

RECOMMENDATIONS:

(1) Add the language on access included in the PAMI reauthorization of 1988 which deals with death reports and reports of persons whose whereabouts are unknown.

(2) Add PAMI statutory language on the definition of reports. As used in this section, the term "records" includes reports prepared by any staff of a facility rendering care or treatment or reports prepared by an agency charged with the investigating reports of incidents of abuse, neglect, injury occurring at such facility or death and the steps taken to investigate such incidents, and discharge planning records.

(3) P&A systems must have access to facilities in the state providing treatment, services, and/or habilitation to people with developmental disabilities regardless of whether a complaint on behalf of a resident of such a facility has been received or whether probable cause has been established.

(4) P&A agencies should have access to the name and address of the legal guardian of a person with developmental disabilities for the purpose of:

(a) informing the guardian that a complaint has been received or that there is probable cause to believe that the ward has been subject to abuse or neglect;

(b) assisting the guardian in assessing appropriate administrative or legal remedies to resolve the complaint or condition.

(c) P&As should have the authority to take action on behalf of the ward if the guardian refuses to act.

(5) Provide all P&As with the death reports of all persons who have died while residents of state operated or supported facilities.

O ISSUE 5: PROGRAM INCOME. Currently, P&A's are allowed to use income from attorney fees and other income generated by their activities to further the aims of the program. Reliable sources indicate that OMB will issue new rules that will adversely affect the ability of federal agencies to use fees in this manner.

RECOMMENDATION: Develop statutory language assuring that program income may be used to further the goals of the program and not be reverted to the federal treasury.

O ISSUE 6: DESIGNATED AGENCY RECEIVING FUNDS. Information from ADD officials indicate that some policy makers believe it is inappropriate for non-state agencies to receive federal formula grant moneys directly even though the P&A systems have been doing so since the inception of the program in 1977.

RECOMMENDATIONS:

(1) Include statutory language similar to language contained in the Rehabilitation Act pertaining to Client Assistance Programs which states that the designated agency should receive the funds directly from the federal agency.

(2) At the very least, include language which refers to non-profits as in the PAMI act concerning governing boards and which imply that non-profit agencies are legitimate entities to carry out the P&A mandate.

0 ISSUE 7: AUTHORIZATION LEVELS. The need for increased P&A funding continues to grow rapidly especially with the passage of several new initiatives by Congress, i.e. OBRA 87 - Nursing Home Reform, the Fair Housing Act, implementation of the early childhood programs, as well as the potential passage of the Americans with Disabilities Act. P&As are forced now to set priorities for service which eliminates from service many persons who have developmental disabilities.

RECOMMENDATIONS: Beginning with the previous authorization levels, provide percentage increases over FY 1990 for the next three years which will adequately address the advocacy needs of persons with developmental disabilities.

For FY 1991, an authorization level of $27 million, $28.35 for FY 1992 and $29.77 for FY 1993.

PART D - UNIVERSITY AFFILIATED PROGRAMS

(Note the following programmatic areas are listed in order of priority, not the order in which they appear in statute.)

0 ISSUE 1: UAP EXPANSION. CCD believes that a broad series of factors should govern expansion of the UAP network. In order to protect the interests of currently unserved states, lack of a UAP is specifically listed as a criterion which the Administration of Developmental Disabilities must take into account when considering an application for an additional UAP. Unserved states now include Arizona, Alaska, Delaware, Maine, New Mexico, Nevada, North Dakota, Oklahoma, Rhode Island, Wyoming and Puerto Rico (the largest territory). In addition, we seek statutory language which will clarify ADD's authority to fund multiple-site UAP applications.

RECOMMENDATION: Section 153 (d)(3)(A) - For the purposes of making grants under section 152(a), the Secretary shall consider applications for grants for four university affiliated programs or satellite centers for each of the fiscal years 1991, 1992 and 1993 which are in addition to the total number of university affiliated programs and satellite centers receiving grants under such section for the preceding fiscal year.

(B) Such programs and centers shall, to the extent feasible, be geographically distributed for the purpose of serving States and geographic regions that are unserved by university affiliated programs and satellite centers receiving grants under such section for the preceding fiscal year. In judging grant applications, the Secretary shall consider the absence of a university affiliated program in the state or immediate geographic region, the quality of the application and such factors as the total estimated number of persons with developmental disabilities, including those traditionally unserved or underserved, in the state or immediate geographic region; the presence of significant rural populations or urban minority populations; the commitment of local, state and university resources; the population density of the state or immediate geographic region to be addressed by the application and the size of the state or geographic region to be addressed by the application. The Secretary shall solicit and may approve an application under this section which encompasses multiple universities within the same state university system or two or more universities which are otherwise unrelated.

(C) Strike section 153(3)(C), since rural populations are addressed immediately above.

RECOMMENDED REPORT LANGUAGE: $750,000 needs to be earmarked to authorize three (3) new UAPs in FY 1991. If the existing core administrative award is not increased, the total cost would be $600,000.

0 ISSUE 2: EXISTING TRAINING PROGRAMS. At present UAP core administrative awards and the three mandated training initiatives are funded through separate line-items. While CCD recommends that the latter line-item be retained, we also propose that it now be used to make permanent and separate "core training awards" within each UAP at a proposed funding level of approximately $90,000 to $100,000 per program.

RECOMMENDATION: Section 152(b)(1) - From amounts appropriated under section 154(b), the Secretary shall make grants of no less than $57,000 and no more than $100,000 to all university affiliated programs receiving grants under subsection (a) to support personnel preparation projects to train allied health personnel, other personnel and families to address the training and service needs of persons with developmental disabilities. Such grants shall be restricted to --

(i) Grants to assist university affiliated programs in providing training to allied health personnel and other personnel who provide, or who will provide, interdisciplinary early intervention services to infants, toddlers, and preschool age children with developmental disabilities. Such training projects shall include instruction on methods of working and collaborating with education and other professionals and families of persons with developmental disabilities.

(ii) Grants for training projects to support the planning, design and implementation of coordinated interdisciplinary training programs between existing aging or gerontological programs and university affiliated programs in order to prepare professional staff to provide services to elderly persons with developmental disabilities.

(iii) Grants for training projects to provide interdisciplinary training to personnel who will provide direct support and services for persons with developmental disabilities, including paraprofessionals who are employed or are preparing to be employed in community-based day programs or residential programs. The Secretary shall ensure that all grants under this paragraph are made only to university affiliated programs that involve local community-level direct care programs and paraprofessional training programs in the preparation of the application for such grant and shall ensure that any training under the university affiliated program will be coordinated with local programs.

(2) A university affiliated program, having the sole and exclusive authority to select among the three training areas provided for in this subsection, shall do so in consultation with the State Planning Council for the state in which the university affiliated program in located and interested consumer, provider and advocacy organizations. Once a selection has occured, a university affiliated program must engage in ongoing training activities in the priority area selected for at least three full fiscal years. This subsection will be deemed to take effect on June 30, 1990.

Strike section 152(b)(1)(B), and (C), (C)(2), (C)(3) and (C)(4) and insert the following A university affiliated program will not be eligible to receive training funds, as described in section 152(b)(1), until it has completed at least one full fiscal year of operation.

RECOMMENDED REPORT LANGUAGE: The Committee intends to both insure the continuity of the personnel preparation programs authorized by section 152(b) as well as enhance the prospects that state and local service agencies will invest staff and resources in them. While the development of curicula and other training materials is of critical importance, the impact of these three training programs is largely dependent upon the involvement of the State Mental Retardation/Developmental Disabilities Agencies, State Departments of Education, and the various State agencies responsible for administering the Older Americans Act. Their active participation helps to ensure that the training is actually delivered to the professionals, direct care staff and families who need it most. Moreover, in order to sustain a maximum systemic impact, it is expected that the Secretary will make training grants of at least $100,000 for each UAP if resources are available in section 154(b).

In addition, the Committee encourages the Secretary, through the Administration on Developmental Disabilities, to continue the development of fiscal and quality review criteria for training programs in early intervention, aging and paraprofessional personnel preparation. It is anticipated that such training will continue to be value-based and adhere to state-of-the-art competency requirements. The only way a UAP can lose a core training award is failure to meet agency fiscal and quality standards; such awards will not be subject to competition.

RECOMMENDED REPORT LANGUAGE: The projected cost for Section 152(b)(1) is $1.6 million in new funding for FY 1991. Since $2.794 million is already being obligated to support 31 UAPs, an additional $1.6 million would be needed to bring total spending on core training awards to $4.394 million, which is within the FY 1988 authorization ceiling. The additional resources would be used to provide personnel preparation funds to the 16 UAPs without specialized training programs in the three areas.

0 ISSUE 3: NEW TRAINING INITIATIVES. CCD proposes five new training initiatives critically needed in the field -- in behavior management, state-based training, assistive technology, prevention and children with HIV infection. These are all emerging areas that are being insufficiently addressed by other authorities.

RECOMMENDATION: Section 152(f)(1)(A). From amounts appropriated under section 154(e), the Secretary shall make grants to university affiliated programs receiving grants under subsection (a) to support training projects to train personnel to address the needs of persons with developmental disabilities in areas of emerging national significance, particularly projects to train personnel in the areas of positive behavior management programs (as described in paragraph [2]), state initiated training programs (as described in paragraph [3]), programs to prevent and/or ameliorate developmental disabilities (as described in paragraph [4]), programs providing assistive technology to persons with developmental disabilities (as described in paragraph [5]), and programs serving children with HIV infection (as described in paragraph [6]).

(B) No grants may be made under section 152(f) unless the total amount appropriated for subsections 152(a),(b) and (d) is at least $17,200,000.

(C) Grants under this section, which shall be no less than $100,000, may be used by university affiliated programs to (i) assist in paying the costs of courses of training or study for personnel to provide services for persons with developmental disabilities and (ii) establish fellowships or traineeships providing such stipends and allowances as may be determined by the Secretary.

(D) Subject to subparagraph (B), of amounts appropriated under section (f) for any fiscal year, the Secretary shall make at least three grants in each subsection in the following order of priority.

(2) Grants under this subsection for training projects with respect to positive behavior management interventions shall be for the purpose of assisting university affiliated programs in providing training to families, foster parents, paraprofessionals, other appropriate community-based staff, institutional staff including medical professionals, behavioral therapists and psychologists who provide, or who will provide, positive behavior management interventions for persons with developmental disabilities. Such training shall include ethical principles and standards; appropriate assessment of the origin of behavior problems including antecedent behaviors, the environment, medical problems including seizure disorders, other neurological problems, or medication side effects; the development of a behavior modification plan; the use of positive reinforcements appropriate to the developmental level of the individual; the use of emergency procedures; and the administration of appropriate psychotropic drugs and their potential interactions with other drugs the individual may be taking for other conditions such as seizure disorders. Grants under this subsection shall be no less than four years in length.

(3) Grants under this subsection with respect to state initiated training programs shall be for the purpose of addressing training deficits identified jointly by university affiliated programs and State Planning Councils. Such training projects should be directed at the training needs of traditionally unserved and underserved populations of persons with developmental disabilities.

(4) Grants under this subsection with respect to assistive technology shall be for the purpose of assisting university affiliated programs in providing training to allied health personnel and other personnel who provide, or who will provide, assistive technology services to persons with developmental disabilities. Such projects may provide training and technical assistance to improve the quality of service delivery in community-based, nonprofit consumer and provider service programs for persons with developmental disabilities and shall be authorized to receive stipends and tuition assistance from such organizations. Grants under this subsection shall be no less than four years in length.

(5) Grants under this subsection with respect to prevention programs shall be for the purpose of training allied health personnel and other health care providers in techniques designed to prevent or ameliorate developmental disabilities. Such training shall include (i) interdisciplinary developmental screening of infants, toddlers and young children; (ii) standard genetic counseling with special emphasis on low-income families and (iii) effective early intervention service techniques for children with developmental disabilities.

(6) Grants under this subsection with respect to children with HIV infection shall be for the purpose of assisting university affiliated programs in training allied health professionals, foster parents, families, paraprofessionals, educators and social workers in providing health, developmental and residential services and counseling to infants, toddlers, young children and women of child bearing age with HIV infection. Such training shall be offered on both a preservice and inservice basis.

RECOMMENDED REPORT LANGUAGE: For Section 152(f) $5.5 million over several fiscal years is needed. Due to the expense of assistive technology training programs, this initiative should be funded at $1.5 million while the remaining training programs be supported at $1.0 million per program.

0 ISSUE 4: UAP CORE FUNDING. With the exception of a $25,000 core funding increase per program approved by Congress three years ago, the UAP network has not received enhanced administrative resources for over 15 years. Using standard consumer inflation estimates for that period, it's safe to say that it is the real value of UAP core awards are less than half of what they were in 1975. $2.4 million would be needed in FY 1991.

RECOMMENDATION: Section 152(d) is amended by striking out $200,000 in paragraph (1) and inserting in lieu thereof "250,000." Grants under this section made on or before July 1, 1989 may not be reduced.

0 ISSUE 5: UAP RESPONSIVENESS. In order to insure UAP responsiveness to the service needs of primary consumers and the personnel preparation requirements of state agencies, CCD proposes that each UAP establish a consumer advisory committee.

RECOMMENDATION: Section 152(g) - No grants may be made under Section 152 unless an application thereof contains provisions for the establishment of a consumer advisory committee. Each such committee shall consist of at least one person with a developmental disability, a parent or guardian of a person with a developmental disability, representatives from both the State Planning Council established under section 124 and the State protection and advocacy system established under section 142, a representative from a community provider agency, and representatives from the principal state agencies (including, but not limited to, the State agency that administers funds provided under the Rehabilitation Act of 1973, the State agency that administers funds provided under the Education of the Handicapped Act, and the State agency that administers funds provided under Title XIX of the Social Security Act for persons with developmental disabilities). As appropriate, State agencies providing financial support to the training programs under section 152(b) are authorized to participate.

0 ISSUE 6: AUTHORIZATION OF APPROPRIATION. In order to implement the agenda described above, changes will be needed in the UAP authorization figures. When reading the funding totals below, note that subsections 152(a) and (d) support administrative core awards and UAP expansion, while (e) provides the authority for feasbility studies. Subsections 152(b) and (c) constitute the line authority for the existing training programs and ADD discretionary funds within the UAP account.

CCD proposes a single additional line item (Section 152(f)) to support the five new discretionary training initiatives described under Issue #3. $10.35 million in total additional federal funding will be needed for all the items listed above. Note that over half this total (i.e., $5.5 million) stems from the five new training initiatives. CCD is aware that it may require several fiscal years of concentrated effort to acquire federal financial support for these important training programs and recognize that all of these funds may not be available in FY 1991.

RECOMMENDATION: Section 154 (a) For the purpose of grants under subsections (a),(d) and (e) of section 152, there are authorized to be appropriated $13,150,000 for fiscal year 1991, $13,750,000 for fiscal year 1992, and $14,350,000 for fiscal year 1993. Amounts appropriated under this section for a fiscal year shall remain available for obligation and expenditure until the end of the succeeding fiscal year.

(b) For the purpose of grants under sections 152(b) and 152(c), there are authorized to be appropriated $4,500,000 for fiscal year 1991, $5,000,000 for fiscal year 1992, and $5,500,000 for fiscal year 1993.

(c) The Secretary may use funds appropriated under subsection (a) for the purposes described in subsection (b).

(d) Of amounts appropriated under subsection (b), at least 75 percent shall be used for grants under section 152(b) and the remainder shall be used for grants under section 152(c).

(e) For the purpose of grants under section 152(f), there are authorized to be appropriated $5,500,000 for fiscal year 1991, $5,500,000 for fiscal year 1992, and $5,500,000 for fiscal year 1993.

PART E - PROJECTS OF NATIONAL SIGNIFICANCE

SECTION 161 - PURPOSE

0 ISSUE 1: CLARIFY PURPOSE. The purposes of the projects of national significance are insufficiently specific to provide guidance to the Administration about the needs in the field. While there have been recent improvements in the Administration's management of these grants and contracts, the excess discretion afforded the Administration has frequently resulted in the funding of activities which are not on the "critical path" in the field. The language below provides explicit areas to be funded by this authority. There is broad agreement in the developmental disabilities community that the scarce dollars under this authority should be targeted to the highest priority needs where impact can be greatest. Areas for funding are specified in the purpose statement of the program. In addition, throughout the 1980's the Office of Human Development Services has combined the processes and funds for the discretionary programs that its sub-units administer - the Administration on Developmental Disabilities, the Administration on Aging and the Administration on Native Americans. This practice has led to a lessening of focus on the greatest needs in developmental disabilities. Although Congress has expressed its intent in report language that this practice should cease, it has continued.

RECOMMENDATION: Section 161. The purpose of this part is to provide for grants and contracts for projects of national significance to increase and support the independence, productivity and integration into the community of persons with developmental disabilities and to support the development of state and national policy which enhances the independence, productivity and integration of people with developmental disabilities through data-collection and analysis, technical assistance to program components, technical assistance for the development of information and referral systems, educating policy-makers, federal interagency initiatives, and the enhancement of minority participation in public and private sector initiatives in developmental disabilities.

RECOMMENDATION: Develop statutory language prohibiting ADD Projects of National Significance from being combined with other OHDS programs for purposes of priority setting and application process. Also develop report language which encourages continued inter-agency funding of developmental disabilities related projects within HHS as well as with the agencies.

SECTION 162 - GRANT AND CONTRACT AUTHORITY

0 ISSUE 2: SPECIFY TYPES OF PROJECTS. Current law is inexplicit regarding whether any or all of the topic areas described will be funded. CCD feels that some of these areas are so critical that the Administration should be required to ask for applications and that others, also important, should be funded as appropriations permit. Also, the requirement for single-year projects thwarts the continuity of many important activities. Mercurial non-statutory initiatives force on-going data collection and analysis to needlessly compete with non-priority projects. Projects in Section 162 should be mandatory and multi-year. Those in a new Section 163 are permissive and may be funded once a trigger amount is achieved in appropriations.

Three invaluable on-going data sets have been up-dated annually, contributing greatly to the development of policy in developmental disabilities. Sections 162 (a)(i), (ii), and (iii) are intended to permit the multi-year funding of these data-sets and to ensure their continuity.

In 1987, Congress mandated that State Developmental Disabilities Councils conduct surveys of consumer satisfaction with services. Councils voluntarily used a coordinated approach and survey design, resulting in an extensive data-set of responses from more than 14,000 individuals with developmental disabilities and their families. The first analysis of this rich data-base will be included in the 1990 Report to Congress mandated in the 1987 amendments. It will take years to fully benefit from the huge amount of data still to be analyzed. Item 162(a)(iv) ensures that this data-set will not be lost, will enable further analysis as well as the exploration of improved techniques for consumer-based policy research.

Section 162(a)(v) addresses a major gap in information in the developmental disabilities field. As a result of the 1990 Reports, DD Councils assessed the impact of services and supports funded by federal and state governments. While there was no requirement that personnel needs be evaluated, most Council Reports repeatedly mention current and projected manpower shortages and problems. There must be a systematic evaluation of the field's manpower needs for the foreseeable future to enable the community to have the capacity to appropriately provide services and supports to people with developmental disabilities. It is critical that this be done on a national basis.

Section 162(a)(vi) mandates data collection on the outcomes of the three programs authorized by the DD Act, the Basic State Grant, Protection and Advocacy Systems and University Affiliated Programs. Such data collection has been sporadic over the years, thus there has been insufficient information describing how the programs operate and what they need to be more effective. This is an essential role of Projects of National Significance.

Section 162(a)(vii) mandates that the Administration fund a project to plan the future direction and scope of data-collection under this part. The dollars are scarce for this authority, making it critical that data-collection efforts are clearly targeted toward the field's highest priorities as described in Sections (a)(i) through (vi). The field needs to provide guidance to the Administration regarding these important information and data needs.

RECOMMENDATION: Section 162. The Secretary shall make grants to and enter into contracts with public or nonprofit private entities for multi-year projects of national significance relating to:

(a) the development of an on-going data collection and analysis system related to the needs and capabilities of people with developmental disabilities, including projects on

(i) federal and state program expenditures for people with developmental disabilities

(ii) residential services and supports for people with developmental disabilities

(iii) trends in employment of people with developmental disabilities

(iv) further analysis of the national consumer survey data including analysis of data regarding those unserved and underserved and refinement of consumer-based data collection methods

(v) the assessment of manpower needs for community-based services and supports

(vi) the performance and effectiveness of the State DD Planning Councils, the Protection and Advocacy Systems and the University Affiliated Programs

(vii) the goals and work-plan for future development of the data collection and analysis system

RECOMMENDED REPORT LANGUAGE: "Regarding Section 162(a)(vii), when developing the goals and work-plan for the future development of the data collection and analysis system, the Secretary should consider the data-collection problems identified by State Planning Councils in their 1990 Reports, including varying eligibility criteria and other factors which tend to exclude or fail to take into account unserved and underserved groups of people with developmental disabilities."

RECOMMENDED REPORT LANGUAGE: "Specific minimum funding levels are recommended for the data collection efforts under Section 162(a) as follows: $200,000 for (i), $200,000 for (ii), $200,000 for (iii) $200,000 for (iv), $160,000 for (v), $300,000 for (vi), and $160,000 for (vii)."

0 ISSUE 3: SPECIFY TRAINING AND TECHNICAL ASSISTANCE FOR PROGRAM COMPONENTS. The frequently changing provisions of the DD Act have modified the roles, scope and functions of the Developmental Disabilities Councils, Protection and Advocacy Systems and University Affiliated Programs. There is a need for on-going reliable technical assistance to and back-up for the program components and they should not be forced to compete with one another or other projects of national significance for such essential assistance.

RECOMMENDATION: Minor changes are recommended in the language of the Technical Assistance Projects section. These projects are among those which need to be mandatory.

(b) technical assistance projects (including research, training and evaluation in connection with such projects) which hold promise of expanding or otherwise improving the (advocacy) functions of the State DD Planning Councils, the (functions performed by) University Affiliated Programs and satellite centers under part D, and the Protection and Advocacy Systems.

0 ISSUE 4: FOLLOW-UP TO INFORMATION & REFERRAL INTIATIVE. The 1987 amendments authorized feasibility studies for the development of a nationwide information and referral system. The two projects that were funded have just completed their evaluations. The CCD member organizations feel strongly that this effort must be directed toward the provision of technical assistance to the States to assist them in the development of locally-based state-wide systems of information and referral. The DD Council 1990 Reports identify this need as well.

RECOMMENDATION: Section 162(c) the provision of technical assistance to states and territories regarding the development of locally-based state-wide information and referral systems.

O ISSUE 5: IMPROVE PROVISIONS ON EDUCATING POLICY-MAKERS. One of the fundamental roles of the Developmental Disabilities Act Programs is to provide information to policy-makers. Although this activity has been in the law since 1987, few significant projects have been undertaken. CCD believes that this critical area needs to be mandated for funding.

RECOMMENDATION: Section 162(d) educating policy-makers regarding the needs and capabilities of people with developmental disabilities and their families, particularly those who are unserved and underserved;

O ISSUE 6: UNSERVED AND UNDERSERVED. As a result of the 1990 Report process, the field is now aware of the many unmet needs among people with developmental disabilities and those who are unserved and underserved. There is a need to mandate further and more specific work in this area. People-first language is also recommended.

RECOMMENDATION: (e) and other projects of sufficient size and scope which hold promise of expanding or otherwise improving opportunities for persons with developmental disabilities especially those who have multiple disabilities or who are disadvantaged, including minority groups, Native Americans, Native Hawaiians, and other unserved and underserved groups.

RECOMMENDED REPORT LANGUAGE: "A major unserved population is that of Native Americans, who particularly need improved access to protection and advocacy services. This need is especially acute on reservations. Despite efforts to provide services by P&A agencies which have large Native American populations within their states, many cultural barriers prohibit this population from receiving their rightful representation. The barriers to this service include the distance of reservations from population centers and P&A offices, the lack of staff who are fluent in the language of the tribes, the special laws which govern some Native American services, the tribal court system and the basic lack of trust for 'outsiders' who attempt to work with the reservation."

RECOMMENDED REPORT LANGUAGE: Regarding section 162(e), only four states (Hawaii, Rhode Island, Maryland and New Jersey) have legislation which uses the federal functional definition of developmental disabilities for state-financed service eligibility (with slight modifications.) Each state has had difficulties in implementation. Other states have somewhat similar definitions. As a result of the 1990 Report process, some State Planning Councils are considering pursuing its adoption as one potential solution to serving the unserved and underserved. On the other hand, many states also have programs for special populations, such as people with autism, cerebral palsy, head injury, epilepsy, etc; thus might stand to lose eligibility for these services if available for only those who meet the federal functional definition of developmental disabilities. It can also create many jurisdictional problems at the state level and further complicate access for potential users of services.

The issue of access to and eligibility for services and supports is an extremely complex one and has been investigated in depth by DD Councils in their 1990 Reports, with a variety of solutions being proposed. It is important to note that the use of the federal functional definition for purposes of eligibility determination for services is not a national recommendation arising out of the 1990 reports. This is not surprising, given the variety of service configurations which already exist.

Under this project authority, a grant of national significance should develop a study to assist States to develop measures to assess functional limitations, which more and more frequently are used by state and federal programs to establish eligibility in lieu of categorical disabilities. The states which have already changed and those which are contemplating a change in their state DD definition should be involved in this study. Clarification of these issues would also provide DD Councils, P&As and UAPs with further information to review and would enhance their advocacy for all people who meet the federal functional definition.

O ISSUE 7: INTER-AGENCY PROJECTS. The following recommendations would permit the Administration to fund projects which take advantage of new opportunities among federal agencies. Current language has also been up-dated. In addition, it is very clear that much needs to be done to increase the participation of minorities in the provision of services and in advocacy organizations, since minorities are among those most unserved. Once appropriations reach a trigger amount, the Administration could fund projects in these two areas.

RECOMMENDATION: Section 163. The Secretary may make grants to and enter into contracts with public or nonprofit private entities for projects of national significance relating to:

(a) the development of federal-interagency initiatives which enhance the independence, productivity and integration into the community of people with developmental disabilities.

(b) training and outreach to increase the participation of minorities in the provision of services, supports and other assistance to people with developmental disabilities and their families and their involvement in advocacy organizations.

O ISSUE 8: PROGRAM FUNDING. Authorization of appropriations for Grants of National Significance has been woefully inadequate. This authority is one of the only foci for national leadership for developmental disabilities. The program has been continuously underfunded and CCD feels this trend must be reversed. CCD further believes that funding targets must be specified in statute to assure that each of these high priority activities are undertaken. The CCD further recommends a trigger which, once reached, would permit projects in the two discretionary areas under Section 163 to be funded.

RECOMMENDATIONS: Section 164 (a) To carry out this part, there are authorized to be appropriated $3,900,000 FY 1991; $4,095,525 for FY 1992; and $4,299,750 for FY 1993.

(b) Of the amounts appropriated under Section 164 for Section 162 at least the following amounts shall be available annually. For subsection (a) $1,420,000, for subsection (b) $400,000, for subsection (c) $200,000, for subsection (d) $400,000 and for subsection (e) $400,000.

(c) The Secretary shall award grants and contracts under Section 162 (a) and (b) for such projects within 6 months after the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990.

(d) In any case in which amounts appropriated under Section 164 for a fiscal year exceed $2,840,000, the Secretary may award grants and contracts under Section 163 (a) and (b).